An exploratory analysis of spatial variations in organ donation registration rates in Wales prior to the implementation of the Human Transplantation (Wales) Act 2013

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Conflict of Interests

None declared.

Abstract

Spatial variations in rates of registered organ donors have not been studied in the UK at detailed spatial scales despite some evidence of national and regional differences. By drawing on the findings from the existing literature, this study examines associations between small-area variations in rates of new registrants to the UK organ donor register (ODR) within Wales and key demographic factors. Using map-based visualisations and statistical regression methods, spatial patterns in new registrants to the ODR are identified within Wales, a country which moved to an opt-out system of consent for organ donation following the Human Transplantation (Wales) Act 2013. By identifying the underlying factors associated with trends in rates of new ODR sign-up, this study aims to highlight the types of approaches that could be used to help to inform future targeted interventions aimed at improving registration rates.

Keywords: Organ Donation Register; Spatial Variations; OLS techniques; Geographical Information Systems; Targeted Interventions.

Highlights

- Motivations for registering as an organ donor are likely to be multifaceted and complex
- National variations in organ donation registration rates within the UK
- Few studies to date examine variations in registration rates at detailed spatial scales
- Study uses potential explanatory variables to find associations in Wales
- Spatial patterns revealed can inform future intervention campaigns

1. Introduction

Globally, the demand for transplantable organs continues to outweigh the available supply with thousands of people currently on waiting lists throughout developed countries (Domínguez-Gil and Matesanz, 2017). In the UK, recent activity figures show that despite an encouraging 4% annual increase in the number of organs available for transplant from deceased donors, resulting in around 3,700 transplants in 2016/17, more than 6,000 patients remain on the transplant waiting list (NHS Blood and Transplant [NHSBT], 2017a). Procedurally, there are many challenges to the procurement and transplantation of organs - from identifying potential donors and obtaining consent, to considerations of organ-patient suitability and the logistics of transporting organs between places. Registering as an organ donor enables a person to make clear their willingness to donate their organs after death and can greatly assist the process of procurement. By the end of March 2017, 23.6 million people had opted to join the UK Organ Donation Register (ODR); representing 36% of the population (NHSBT, 2017a). In the UK, familial consent is required before any organ can be procured for transplant, regardless of the prior wishes of the deceased. Whilst recent authorisation rates suggest consent is granted in almost two-thirds of cases, this rises to over 90% when the patient's ODR status is known (ibid). Of the 1,413 deceased UK donors whose organs were made available for transplant in 2016/17, 44% were registered donors (ibid).

At an individual level, motivations for registering as an organ donor are likely to be multifaceted and complex and may involve a combination of socio-economic, religious/cultural and psychosocial factors. For example, level of education, religiosity, donation-related knowledge, positive attitude, social influence, and altruism, have all been identified as factors positively associated with registered donor status (Nijkamp et al., 2008). Table 1 summarises the findings of previous studies of variations in registered donor status. In summary, several US-based studies have also identified larger proportions of registered donors in areas characterised by greater levels of education, as well as areas with higher levels of residential mobility and median household income (Grubesic, 2000; Ladin et al., 2015; Reibel et al., 2016). In contrast, lower levels of donor registration were associated with higher proportions of black, ethnic minority, younger- (under 18 years) or older-aged (above 65 years) residents.

[TABLE 1 INSERTED ABOUT HERE]

Figures released by NHSBT suggest spatial variations in organ donation registration rates may exist within the UK – for example, at national level, registration rates are lower in England (35% of the population), compared with Wales (38%), Northern Ireland (40%), and Scotland (44%: NHSBT, 2017a). Regional variation is also evident between health authorities in England, with higher rates in the south (42%) compared to the north (34%), the midlands and east (34%), and London (29%). Overall, these trends could be taken to suggest the existence of some underlying spatial factors that

require further investigation. Few studies to date, however, have analysed spatial variations in patterns of organ donor registration rates at detailed spatial scales. This is therefore a noticeable gap in the evidence-base, especially considering the known influence of geographical factors on, for example, blood donation rates (Apparicio et al., 2014; Weidmann et al., 2012; Saberton et al., 2009). To redress this gap, the current study provides an analysis of small-area variations in rates of new registrants to the ODR within Wales, UK, using a subset of potential explanatory variables which draw upon the findings from the studies highlighted in Table 1. The aim is to highlight the types of approaches that could be used to help inform future targeted interventions through an analysis of the underlying factors associated with patterns of organ donation registrations.

2. Data and methods

2.1 Registered organ donors

Numbers of new registrants to the UK ODR between 1st January 2010 and 30th November 2015 were obtained from NHSBT, i.e. for the period immediately prior to the implementation of the Human Transplantation (Wales) Act 2013 (HTWA), which introduced an opt-out system of consent for organ donation in Wales (Human Transplantation (Wales) Act 2013).[1] Data were pre-specified at 2011 Welsh lower layer super output area (LSOA) level based on available UK postcodes. Inclusion criteria were registrants aged between 16-70 years (representing 91% of registrants during this time period). The chosen time period was selected for two reasons: firstly, the opt-out system of consent for organ donation came into effect on the 1st December 2015 and, although data has not currently been made available for variations in opt-out rates at detailed spatial scales for Wales since this date, the types of underlying motivational factors associated with registration could conceivably differ following the implementation of this policy. Secondly, an analysis of the full register of registration since its inception in the mid-1990s revealed evidence of likely over-inflated counts within the complete ODR time series such that 5% of LSOAs had 90% or more residents on the ODR, including three LSOAs where numerator ODR counts were higher than the total population of these areas (Figure 1).

[FIGURE 1 INSERTED ABOUT HERE]

It is posited that such over-inflation may reflect ODR updating procedures concerning deceased registrants or tracking registrant migration over time. Limiting the dataset to numbers of new registrants over a near 6-year time period was found to reduce these issues, although there is still a chance of some inflation in numbers. There were no ethical concerns regarding disclosure since

[1] HTWA replaced the previous opt-in system of consent and in so doing Wales has become the first UK-based country to embrace an opt-out system of consent for organ donation. For a more detailed assessment of HTWA, see Douglas and Cronin (2015).

LSOA-level counts of registered organ donors below five are not permitted for release by NHSBT and individuals could not be identified from the information provided. Data were disaggregated into three age groups; 16-24 year olds, 25-44 year olds, and 45-70 year olds. Age groups were selected to enable the inclusion of all Welsh LSOAs within the analysis by avoiding counts of less than 5 registrations per LSOA (in order to achieve confidentiality thresholds). ODR counts were transformed into rates (per 100 population) using 2015 mid-year population estimates from the Office for National Statistics (Office for National Statistics [ONS], 2016). Overall age-standardised rates of new registrants (16-70 year olds) were calculated to correct for differential age distributions among Welsh LSOAs. Here the age distribution of a standard population (in this case, Wales) was applied to the LSOA rates.

2.2 Methods

New-registration rates for 16-24 and 16-70 (age-standardized) year olds were used in the current analysis. The decision to include data for 16-24 year olds within our analysis was due principally to there being less chance of potential bias associated with studying spatial patterns in new registrants for this age group than could be suggested of other age groups – where lower rates of new-registrants may not equate with lower overall ODR rates. For example, low levels of organ donation registration rates among, say, 45-70 year olds in particular LSOAs between January 2010 and November 2015 may not necessarily be indicative of lower rates of registrations overall because many residents within this age bracket may have already signed-up to the ODR at a time pre-dating the study period and thus would not be included in our data set of new-registrants. In contrast, new-registration rates among 16-24 year olds over the study period may better reflect overall spatial patterns in organ donation registration rates among this age group. To explore spatial variations over the time period, new-registration rates were first mapped using the open source Geographic Information System (GIS) software package, QGIS (Quantum GIS Development Team, 2017). OLS regression models were then fitted to explore associations between spatial variations in new-registration rates and a set of explanatory variables drawn from the literature review (described in more detail in Table 2). Spatially autocorrelated residuals, which violate the OLS assumption of independent errors, were identified in both models (Moran, 1950). Similar to other studies (e.g. Ogilvie et al., 2011), an autocovariate term that represented the value of the dependent variable at neighbouring locations was included within each model in an attempt to account for the presence of spatial autocorrelation (see Dorman et al., 2007).

[TABLE 2 INSERTED ABOUT HERE]

The autocovariate (A) at each LSOA (i) is calculated as:

$$A_i = \sum_{j \in k_i} w_{ij} y_j$$

Where y_j is the value of the dependent variable y at location j among all locations contiguous with LSOA i, k_i. w_{ij} is the weight given to location j's influence over LSOA i. In this study a binary weighting function is applied where a value of 1 is given if location j shares a single boundary point with LSOA i (not necessarily a boundary line) and 0 otherwise. All statistical analysis was undertaken in R version 3.4.2 (R Core Team, 2017). All weights were calculated using the 'spdep' package (Bivand, 2017).

While the inclusion of the autocovariate term reduced the value of the Moran's I statistic in both models, spatial autocorrelation remained. Thus, for the purposes of comparison, coefficients were also obtained from two alternative approaches to modelling spatial data (spatial lag and error models). For brevity, coefficients obtained from these models are not reported here but directions of associations and significance levels were unchanged, reinforcing confidence in the robustness of the study findings. However, due to the continued presence of spatial autocorrelation, explanatory variables were only deemed to be significant if p-values were at the 0.01% level. Mean-centred explanatory variables were used to alleviate issues of multicollinearity within the model owing to the inclusion of an interaction between Townsend score and education level.

3. Results

3.1 Spatial patterns in rates of new registrants to the ODR

Spatial patterns in new-registration rates (per 100 population) for 16-70 year olds (age-standardized) and for 16 to 24 year olds in Wales are presented in Figures 2 and 3 respectively. Whilst new-registration rates were naturally higher among 16-24 compared to 16-70 year olds, overall spatial patterns were similar. For example, both maps provide evidence of lower registration rates in South-Wales valley areas (areas characterised by ex-coal mining towns and villages). In contrast, higher registration rates were generally identified within LSOAs situated in and around major urban areas in both the north east and south east of Wales, and in areas near the Wales-England border.

[FIGURES 2 AND 3 INSERTED ABOUT HERE]

3.2 ***Regression analysis***

Model coefficients are presented in Table 3. Townsend deprivation scores were significantly negatively associated with new-registration rates among 16-24 and 16-70 year olds, suggesting deprived areas have lower rates of new registrations. In contrast, high levels of education were found

to be positively related to new registration rates for both age groups. Percentage of non-religious residents was also shown to be negatively associated with rates of new registrants, but was only a significant predictor in the age-standardized model. The identification in both models of a significant interaction between deprivation and percentage high education suggests that the strength of the positive effect of high levels of education on new-registration rates lessens at greater levels of deprivation. The autocovariate term was only found to be significant in the age-standardized model. Here the positive association supports the Moran's I statistic of greater clustering among similar values. An examination of standardized Beta coefficients suggests that high education has the greatest effect on new-registration rates.

[TABLE 3 INSERTED ABOUT HERE]

4. Discussion and concluding remarks

This all-Wales study examines, for the first time, small-area variations in rates of newly registered organ donors under the previous policy of opt-in consent. In Wales, an opt-out system of consent is now mandated under the Human Transplantation (Wales) Act 2013 which came into effect in December 2015, replacing the previous opt-in system (Human Transplantation (Wales) Act 2013). The principal motivation for moving to an opt-out system being to increase numbers of organ donation rates to levels comparable with the best performing countries (e.g. Spain, Croatia, and Portugal) where similar systems are in place (Barber and Baker, 2018). Under the new law, all adults living in Wales are presumed to be potential organ and tissue donors unless specifically registering a decision to opt-out of donation – although people are still encouraged to register a decision to opt-in (known as '*express consent*'; British Medical Association, 2017). This approach constitutes a 'soft' opt-out system of consent in that relatives of the deceased are still able to challenge donation regardless of presumed consent or the prior wishes of the deceased. Despite this legislative change (which is also being considered in both England and Scotland: Department for Health and Social Care, 2017; Scottish Government, 2017), it remains important to continue to monitor patterns in opt-in rates in order to better inform targeted strategies aimed at increasing rates in areas with lower numbers of registered donors, especially considering the strong association between registered ODR status and familial consent for donation (NHSBT, 2017). Further impetus for exploring potential drivers of opt-in rates is also provided by Welsh Government's use, post-policy implementation, of a media campaign ('talk about donation') designed to encourage people to register their position on donation.[2]

In summary, results presented here show higher proportions of newly registered donors in areas characterised by high levels of education and lower proportions in more deprived areas and areas with

[2] http://organdonationwales.org/talk/?skip=1&lang=en

more non-religious residents – although the latter was only a significant predictor of registered donor status in the age-adjusted model. Overall, education was found to have the greatest effect of all the factors studied on rates of newly registered organ donors based on examination of standardised coefficients – although, this influence lessened with increasing deprivation. Altogether, these findings are suggestive of similar ecological trends in Wales to those reported by studies in Table 1 - where, for example, higher donor registration was associated in areas with higher income and education levels (Grubesic, 2000; Reibel et al., 2016). The main limitation of this study concerns the use of a sub-sample of the ODR (i.e. newer registrants) rather than total registration rates. Whilst unavoidable, this introduces a degree of bias into the analysis because lower rates of new registrant over the time series may not necessarily be indicative of lower overall rates, but could simply reflect recent targeting activity. Other limitations include potential ecological fallacy concerns regarding the use of area-level data and the inclusion of a limited number of explanatory variables within our statistical model. However, findings presented here are consistent with those of other similar studies and our age-adjusted model explained 50% of the variance in rates of newly registered organ donors within Wales.

Building on these exploratory findings, further in-depth research is required to further understand the reasons for such patterns which could for example draw on the findings of previous studies of the motivations for individuals to register. Alternative explanations may be sought for the lower rates of new-registrations to the ODR evident in more deprived settings such as the higher percentages of non-car owners in these areas. As 58% of sign-ups in 2016/17 were through the UK Driver and Vehicle Licensing Agency (NHSBT, 2017a), a potential avenue for further research could involve a study of variations in the distribution of those registered to drive in Wales. Similarly, given the increasing use of on-line registration, spatial patterns of ODR sign-up rates could be analysed in relation to variations in Internet take-up, should such data be made available at detailed spatial scales.

The findings of this short paper make a number of important contributions. As previously alluded, monitoring patterns of opt-in rates should remain a priority for policymakers in countries with a 'soft' opt-out policy (such as in Wales) due primarily to the ability of families to override deemed consent laws. Based on findings presented here, interventions designed to increase ODR sign-up rates should be targeted in areas of greater deprivation and in those areas with lower rates of new-registrants.[3] Furthermore, it is possible that the ecological determinants of opt-in rates identified in this study could also influence decisions to opt-out of donation. Thus, whilst a dataset on opt-out rates for organ donation under the new policy is not yet available at the small-area level in Wales, it is to be hoped

[3] A large scale randomised controlled trial (RCT) aimed at increasing ODR sign-ups previously found people exposed to messages drawing upon notions of reciprocity and fairness were more likely to register as an organ donor, compared to the control group and those exposed to other message types when visiting a selection of government websites (Cabinet Office, 2013). Similar intervention at more localised levels (e.g. Welsh local authority) could be explored.

that this study could potentially act as a benchmark for future studies seeking to compare geographical patterns in opt-out rates, considering 6% of the Welsh population (approx. 180,000 people) have already opted-out of donation following the implementation of the Act (NHSBT, 2017b). In addition, although the focus of this study has been on registration rather than transplantation rates, if such data were to become available the applicability of these factors for studying organ donation rates could be assessed. Finally, the identification of over-inflation in the complete ODR register may have been an unintended consequence of this paper, but nonetheless assists in highlighting how data collection and maintenance procedures for large administrative data sets must be considered when attempting to draw substantive conclusions from these sources.

Conflicts of interest

None declared.

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Table 1: A selection of relevant studies on correlates of registered organ donor status drawn from the empirical literature

Author-year	Country	Outcome measure	Level of analysis (sample size)	Method	Findings/conclusion(s)
Grubesic, 2000	USA, Ohio	Percentage of designated organ donors (identified via driving license)	Ecological (88 Ohio counties)	OLS regression models *(no spatial autocorrelation)*	Percentage of designated organ donors positively associated with median household income and high education levels, but negatively related to the proportion of black residents. Proximity to organ procurement organisations also shown to be an important mediating factor.
Ladin et al., 2015	USA, Massachusetts	Percentage of designated organ donors (identified via driving license)	Ecological (4,466 census block groups)	OLS regression models *(including spatial dependence model)*	High levels of education and residential mobility were associated with higher levels of organ donor designation. Levels of organ donor designation were shown to be lower in block groups with higher proportions of minority residents, greater residential segregation, or persons aged <18 or >65 years.
Nijkamp et al., 2008	North America, UK, Netherlands, & Germany	Registered organ donors vs. non-registered persons	Individual (varied)	Meta-analysis (24 studies)	Levels of education (college vs. less) and religion (religious vs. non-religious) found to be significantly and positively related to registered donor status. Odds ratios for gender, ethnicity and marital status showed no significant relationship. A weak negative association between age and registration was consistently identified. Other predictors of registration were knowledge, attitude, social influence, family discussion, and altruism. Negative factors included fear of death and organ donation-related fears.
Reibel et al., 2016	USA, northern California	Number of registered organ donors (approx. 3.6m)	Ecological (835 zip code areas)	OLS regression models (plus a K-means cluster analysis)	Controlling for population size, lower numbers of registered organ donors were identified in high minority areas, lower-income areas, and immigrant-heavy areas. Zip codes where residents had higher levels of education were

					found to have greater numbers of registered donors. In addition, significant non-linear factor combinations were also identified; some higher socio-economic status areas had high numbers of registrants despite their racial and ethnic heterogeneity.
Shah et al., 2018	USA, Kentucky	Familial authorised donation vs. familial declined consent	Individual (1,059 potential organ donor referrals)	Case-control comparison. Multivariate logistic regression model	Familial authorisation obtained in 47% of cases. Odds ratios for increased rates of authorisation increased linearly with levels of education and decreased with age. Authorisation was also shown to be more likely if the deceased was a registered donor and had lived in a county with a poverty level below the national average. Donor registration was most strongly associated with higher organ donation authorisation rates
Wakefield et al., 2010	USA, Spain, Netherlands, Switzerland, Hong Kong, China, & Pakistan	Attitudes towards organ donation and donor behaviour	Individual (varied)	Systematic review (33 studies)	Younger people and those with higher levels of education and socioeconomic status more likely to have positive attitudes toward organ donation. Less consistency shown regarding gender, ethnicity, or religious beliefs. One study reported stronger religious beliefs were predictive of less favourable attitudes towards donation. Other predictors of favourable attitudes were better knowledge of organ donation, knowing others with positive attitudes toward organ donation, and altruistic behaviour.

Table 2: Explanatory variables used in the regression analysis

Variable	**Description**	**Source**
Townsend deprivation score	A composite, small-area measure of deprivation based on levels of non-car and non-home ownership, overcrowding and unemployment. An additive measure calculated through the summation of equally weighted standardized z-scores.	Derived from 2011 UK Census data
% High education	Percentage of LSOA population with level 3 UK qualifications or higher.[4]	2011 UK Census
% Non-religious	Percentage of LSOA population specified as atheist.	2011 UK census

[4] For a detailed breakdown of the different UK qualification levels go to: https://www.gov.uk/what-different-qualification-levels-mean/list-of-qualification-levels.

Table 3: OLS regression results (standard errors in parenthesis)

	ODR rates, 16-24 years		**Age-adjusted ODR rates, 16-70 years**	
	β	BETA	β	BETA
Intercept	26.253 (0.150)***		12.868 (0.046)***	
Townsend deprivation score	-0.349 (0.052)***	-0.187	-0.225 (0.016)***	-0.312
% High education	0.169 (0.014)***	0.322	0.080 (0.004)***	0.394
% Non-religious	-0.003 (0.021)	-0.003	-0.040 (0.006)***	-0.128
Townsend deprivation score x % High education	-0.010 (0.003)***	-0.073	-0.003 (0.001)***	-0.057
Autocovariate term	0.004 (0.002)¥	0.041	0.004 (0.001)**	0.048
Adjusted R-squared	0.203		0.495	
F-statistic	98.410***		374.500***	
Moran's I	0.074***		0.141***	

***P<0.001; **P<0.01; ¥P<0.10

Figure 1: Evidence of over-inflation in ODR sign-up rates in the complete register; Welsh residents on the ODR who registered before 1st December 2015

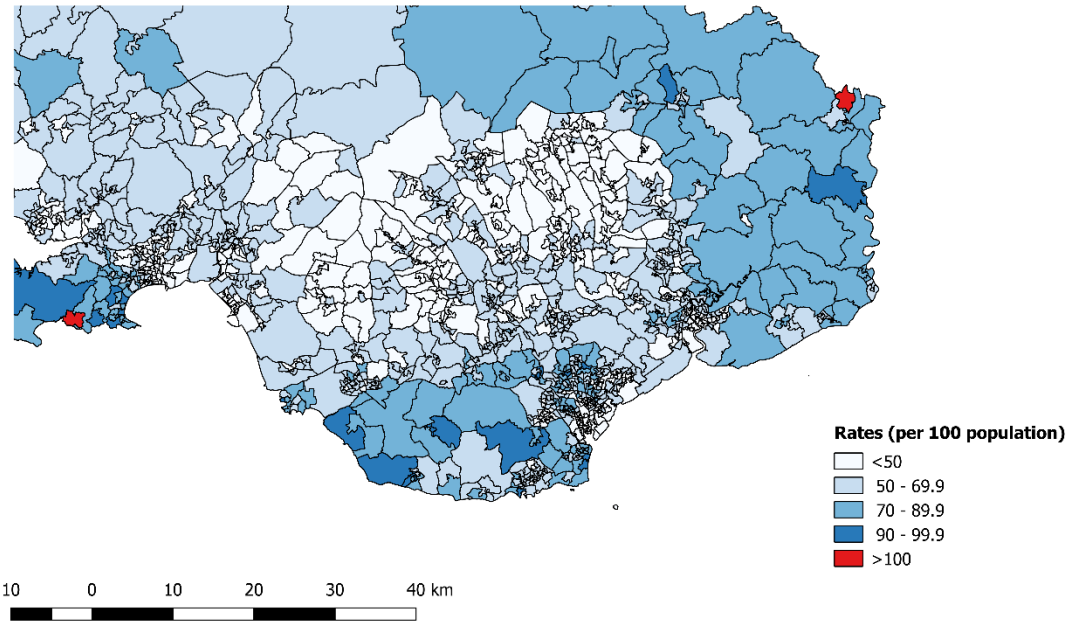
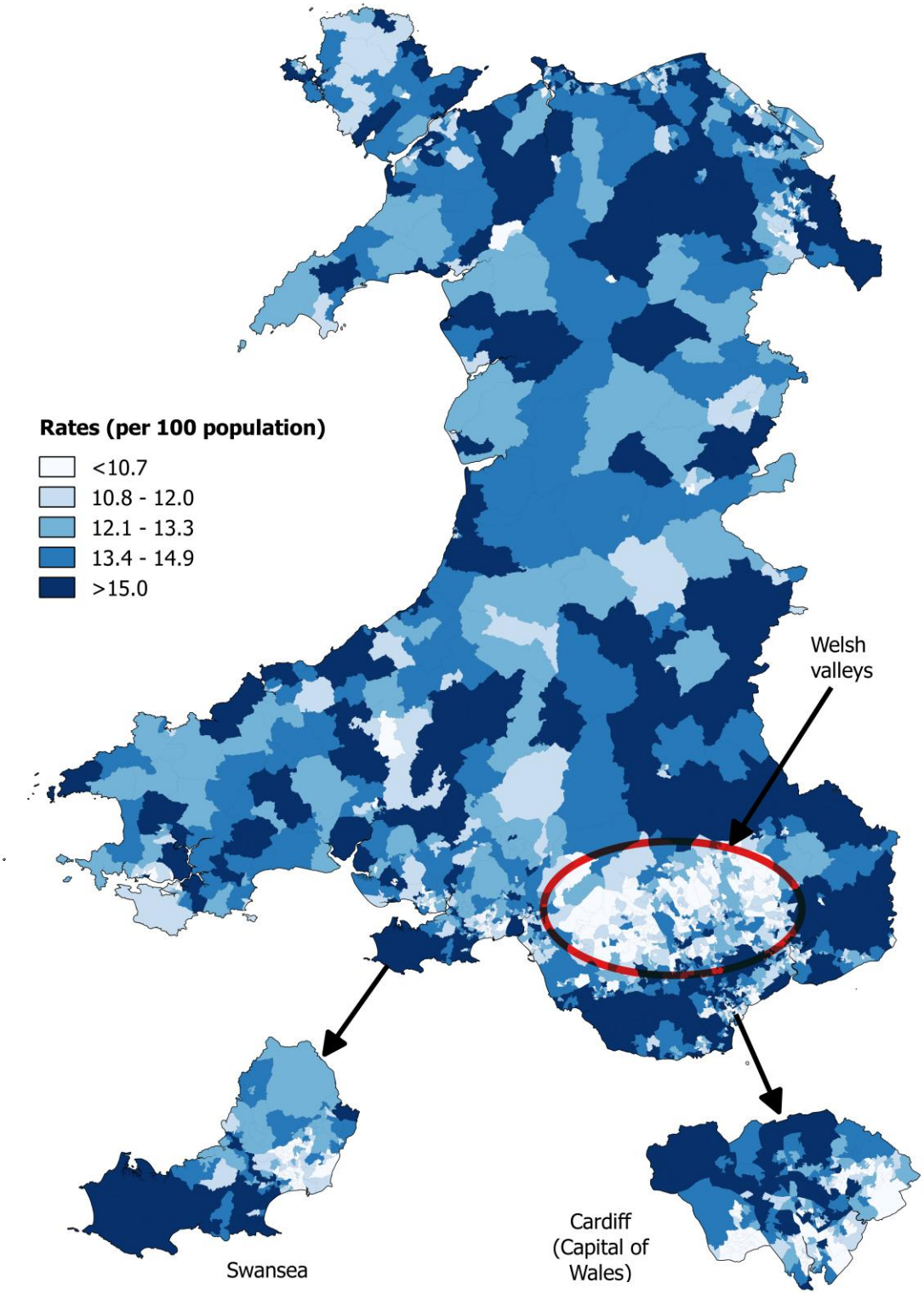


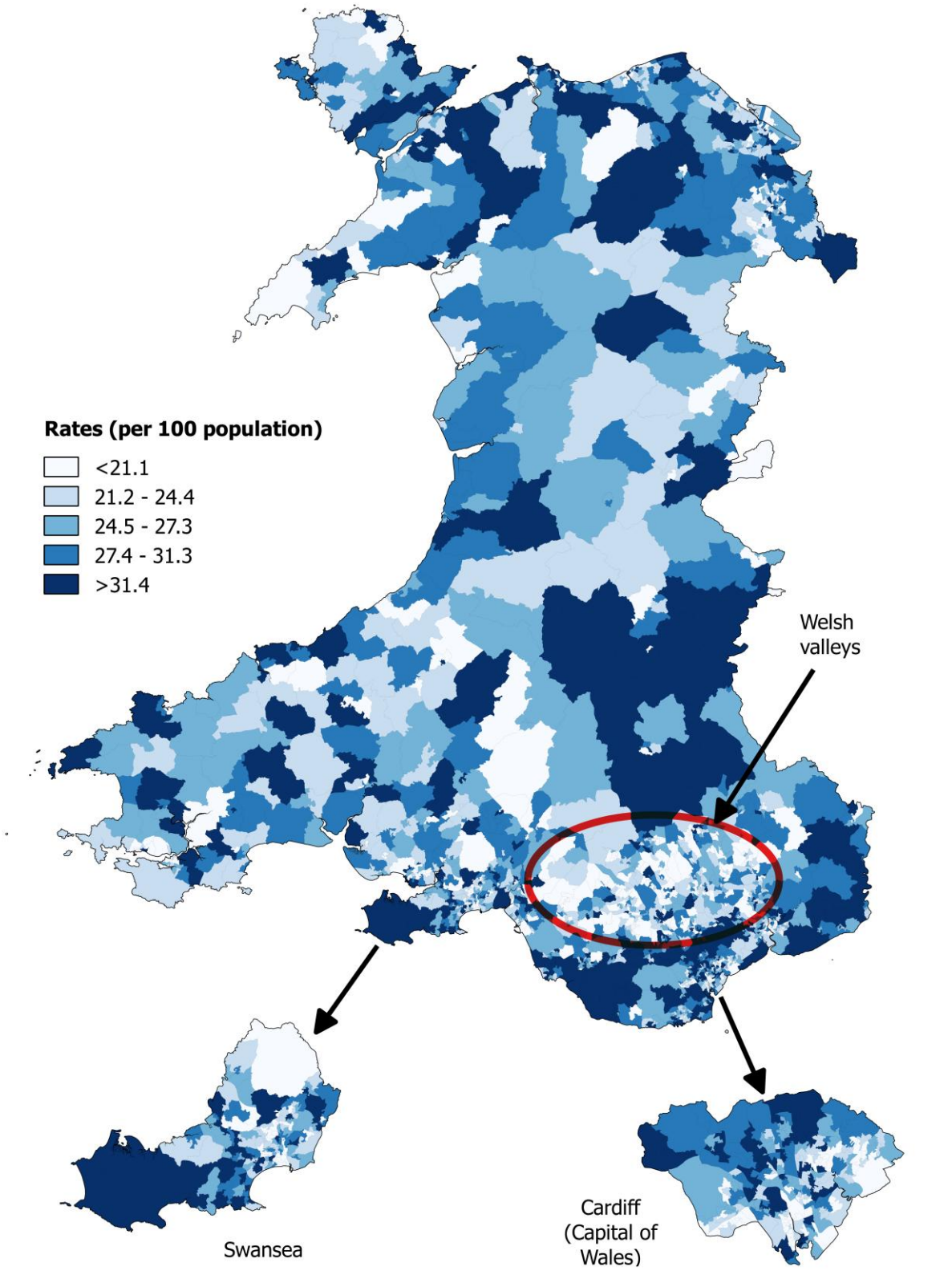
Figure 2: Age-standardized rates (per 100 population) of newly registered organ donors, 16-70 year olds



Sample aged between 16-70yrs (91% of all registrants)

Source: NHS Blood & Transplant

Figure 3: Rates (per 100 population) of newly registered organ donors, 16-24 year olds



Source: NHS Blood & Transplant